

Caregiver perceptions and attitudes associated with oral immunotherapy on social media

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ABSTRACT

Background: Caregiver values and preferences with regard to oral immunotherapy (OIT) for treatment of food allergies are not widely reported. Understanding caregiver perspectives is integral to establishing shared decision-making in the treatment of food allergy.

Objective: We aimed to understand caregiver opinions that may influence caregivers in their decisions about OIT through social media.

Methods: We searched a popular parenting web site for posts related to OIT from December 2008 to September 2019. We applied a Preferred Reporting Items for Systematic Reviews and Meta-Analyses framework to review posts for inclusion, performed thematic content analysis to determine common themes, and calculated frequencies for each theme and subtheme. Posts and comments were included if they contained discussions about OIT for immunoglobulin E-mediated food allergy and were excluded if they were duplicates, comments from an original post from the original user, or comments on a nonrelevant original post.

Results: Of 1300 posts and comments retrieved, 174 were included (13%). Most were excluded because they did not directly address OIT for food allergy. Relevant posts could fall into multiple themes and were categorized under three main themes: attitudes (n = 128, "I am scared to do OIT but scared not to!"), logistics (n = 168, "We will be doing this once LO [little one] is a little older"), and questions (n = 32, "How does it work?").

Conclusion: Caregivers communicate with each other through social media, expressing attitudes, logistics, and questions about OIT. Understanding these lay perspectives may help guide clinicians in counseling and engage caregivers in decision-making.

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Approximately 3 million children in the United States have food allergy.¹ Food allergy affects the quality of life for children.² Strict avoidance in the setting of a positive in-office food challenge is the standard of care for food allergy. Oral immunotherapy (OIT) is an emerging therapy for food allergy. The food allergen is given in an increasing amount over time to increase the amount of protein required to trigger an allergic reaction.³ The U.S. Food and Drug Administration (FDA) approved the first OIT product on January 31, 2020, for peanut allergy.⁴ Before this, OIT was offered to patients in the setting

of research studies or individual practitioners with non-FDA approved products.

There is controversy with regard to OIT for food allergy treatment.⁵ The National Institutes of Allergy and Infection Disease published food allergy treatment guidelines in 2010, a statement that did not recommend use of OIT for children with food allergies because there was not enough information on safety and long-term outcomes of this treatment.⁶ A meta-analysis that assessed the efficacy and safety found that treatment with OIT increased the patient's risk for allergic reaction and anaphylaxis compared with placebo, although it led to effective desensitization.⁷ Private practice or community practice OIT has been available, with one report citing parental conflict about OIT being a relative contraindication.⁸ The European and Canadian food allergy guidelines emphasize the importance of patient motivation for the treatment of food allergies.^{9,10} A meta-analysis that assessed allergen immunotherapy for food allergy concluded it may be effective but also raises risk of reactions.¹¹ Greenhawt *et al.*¹² created a tool for discussion with families when considering OIT, which emphasizes the importance of clarifying what aspect of OIT means the most to patients; the American College of Allergy, Asthma and

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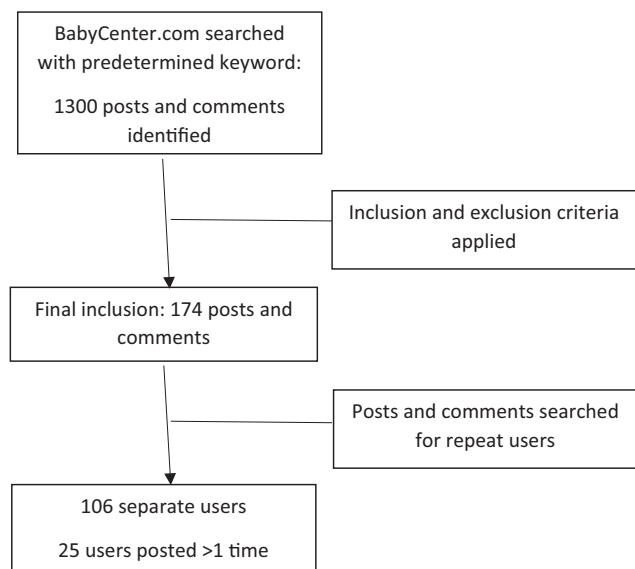


Figure 1. Process of exclusion. The total number of posts represents those that met inclusion criteria versus the total number of posts identified during the initial search. Posts were excluded cumulatively and not on an individual basis. The final flowchart represents the total number of separate users who posted a comment, and 25 users posted more than one time.

Immunology has also published a discussion guide for patients considering OIT.¹³

Shared decision-making is a partnership between the clinician and the family, which may be beneficial when discussing treatments for food allergy.^{14–17} Caregivers often use the Internet when seeking information for medical decisions and knowledge.^{18–20} Understanding caregiver priorities that may not be relayed during health visits may help to acknowledge caregiver questions and possible background bias due to information they encounter on the Internet. Previous studies used posts on social media and parenting web sites to evaluate parental values to better understand decisions parents make about therapies.^{21,22} The current study aimed to identify themes of caregiver perceptions with regard to OIT for food allergy so that clinicians may be better prepared to help navigate the decision for treatment with OIT by evaluating posts available publicly on social media to categorize the factors that drive decision-making for caregivers when considering OIT treatment for their children with food allergies.

METHODS

Data Source and Extraction

We searched posts and comments (responses to original posts) on a popular website which provides a forum for communication among parents and is one of the largest online forums for parenting and pregnancy.^{23–26} Posts included references to older children (“My older

daughter [13] is doing oral immunotherapy for her peanut allergy”) as well as infants (“Also, it’s been done on infants and children with great success”). We included posts from December 19, 2008, to September 1, 2019, to achieve an inclusive understanding of caregiver attitudes with a wide range of posts but avoid confounding results due to the first FDA conference that discussed approval for peanut OIT on September 13, 2019.²⁶ Seventy-five percent ($n = 131$) of the posts were from 2015 to 2019, with the majority of the posts from 2016 to 2017 ($n = 109$ [63%]). A list of 24 search phrases was created by combining a primary phrase (*i.e.*, immunotherapy) with a food-specific qualifier (*i.e.*, peanut, milk, or egg). The full search terms are listed in Supplemental Table e1.

Collected posts and relevant comments were included if they were written in English and contained discussion about OIT for immunoglobulin E-mediated food allergy. Original posts and comments were treated equally to ensure that we captured all opinions with regard to immunotherapy from all users. Each relevant post and its comments were reviewed and included if they met the inclusion criteria. We included some comments that were considered relevant to OIT that may not have been included in the original search because they may not have included a key search term. We excluded posts that were comments on a nonrelevant original post, duplicates (the same post by the same user that appeared in the search multiple times due to different search terms or the same post by the same user posted on a different date or in a different forum), unrelated to OIT for food allergy, expressed no opinion or thought with regard to OIT, or comments on an original post from the original user.

We used the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) method to create a search strategy, as detailed in Fig. 1.²⁷ We aimed to achieve thematic saturation, at which point collection of new posts and data does not contribute meaningfully to the analysis.²⁸ Once saturation is achieved, small sample sizes can be acceptable because this is considered a standard criterion for qualitative methods.²⁹ Van Kaam³⁰ reported that 25 participant descriptions in phenomenologic studies are the minimum sample size requirement, and Guest et al³¹ performed field studies with East African women and determined that saturation was reached within the first 12 interviews.²⁰

Analysis

We performed directed content analysis, wherein relevant posts and comments from a representative sample were initially used to determine thematic content before the complete analysis of all of the posts.³² Ten percent of the data was used to determine themes

Table 1 Framework for thematic content analysis evaluating parent perceptions of OIT

	Attitudes			Logistics			Questions				
	Fears about food allergy	Cross-contamination	Fears about OIT	Child's preference	Ability to eat the food	Physician availability	Clinical trial	Cost	Patient characteristics	Experience	Details
OIT = Oral immunotherapy.											

and create coding categories, and double coded to establish agreement (S.R.K., T.H.). Two researchers (A.R.L., L.E.C.) then coded all included posts. Emergent themes were identified from posts that did not fall into the original categories. Subthemes within the themes were determined (Table 1). Posts within each theme and subtheme were enumerated. Frequencies were generated and percentages were determined by calculating the frequency of the theme or subtheme of the 174 included posts to demonstrate the most common perceptions discussed by caregivers about OIT. Kappa tests were used to obtain an interrater observed agreement percentage to confirm consistency of classification between the coders. Observed agreement of >75% was considered adequate. STATA/SE 15.1 (StataCorp LLC, College Station, TX) was used to perform statistical analysis. The Johns Hopkins School of Medicine Institutional Review Board (IRB00104528) approved this study.

RESULTS

Thirteen hundred posts and comments were identified with the predetermined keyword searches. Some posts contained relevant comments that were not included in the original search but were included in the data extraction. One hundred and seventy-four posts and comments satisfied the inclusion criteria (13%). Most posts were excluded because they discussed other forms of immunotherapy, not related to food allergy (e.g., "DH [dear husband] has a bunch of warts on his hands and instead of freezing them off, the derm suggested using immunotherapy."). This total represented 106 separate users, 25 of whom posted more than one time, with 67 of the 174 posts (39%) as duplicates from a user (Fig. 1). Two major themes were initially identified: attitudes ($n = 128$ [74%]) and logistics ($n = 168$ [97%]) (Table 2). A third overarching theme that identified caregiver "Questions" emerged during content analysis and was included in the coding scheme, with a total of 32 posts (18%) (Table 2).

Twenty-four posts (14%) contained content that was not applicable to the coding scheme but did not reveal any emerging themes ("a friend sent me this article"). Many posts had components that fell into multiple categories and thus were included multiple times in the frequency calculations (e.g., logistics and questions: "We actually have a Dr. that does immunotherapy close to me. Have been considering it for my son's tree nut allergy. Can I ask if your insurance covers any of it?"). There was a cumulative observed interrater agreement of 83.2% for all codes inclusively (individually: sentiment theme, 87%; logistics theme, 78%; questions theme, 85%).

Table 2 Frequency of themes and subthemes and representative quotes for parental perceptions of OIT on social media

Subtheme	Frequency, <i>n</i> (%) [*]	Representative Quote
Attitudes theme		
Fear of OIT	37 (21)	"The trials DID have deaths [by the way] . . . maybe your doctor's specific practice hasn't had any (yet), but it IS a risk."
Eat the food	36 (21)	"OIT offers freedom with eating."
Fear of allergy	30 (17)	"To not DIE when ingesting peanuts. That's the point."
Cross contamination	10 (6)	"In two more visits she'll be cleared for cross contamination and in a year we'll do a peanut challenge. I'm more concerned about cross contamination then her actually ingesting a peanut, so I'm very excited that we've come as far as we have."
Child's preference	8 (5)	"Hardest part was reminding him to eat the few peanuts every once in a while. Some kids don't want to eat them after years and years of being afraid that they would kill them."
Cure	7 (4)	"Has anyone gone through all the rounds and seen their child "cured" of peanut allergy?"
Logistics theme		
Physician availability	79 (45)	"Depending on where you live, OIT may or may not be available nearby outside of a clinical trial (we'd have to drive at least five hours to find a private practice doctor who does OIT."
Characteristics of the child	42 (24)	"Our allergist said that the kids need to be verbal so they can communicate any symptoms they have like a tummy ache when the therapy is given."
Research study	33 (19)	"My daughter may participate in such a study at Stanford."
Cost	14 (8)	"\$1000 in medical bills plus gas bills plus wear and tear on my car. Its not easy. I drive a 4 to 6 hour round trip every week for this."
Questions theme		
People's experiences	23 (13)	"Have you considered immunotherapy before? Why did you do it or not do it?"
OIT details	9 (5)	"How often are your Drs increasing your children's dosage? And by how much?"

OIT = Oral immunotherapy.

^{*}The percentages reported represent the overall frequencies (of 174 posts and comments included).

Attitudes

The overarching theme of "attitudes" captured caregiver emotions and motivations with regard to OIT. The theme included the following subthemes: hope for a cure ($n = 7$ [4%], "I'm so happy that scientists take this condition seriously and are trying to find a cure"), concerns about cross contamination ($n = 10$ [6%], "Cross contamination is awful, and the cheaper the product the less likely they are to keep it safe"), fear of the allergy ($n = 30$ [17%], "the recent food allergy death in the need makes me want to do whatever will help her outgrow this potential death sentence"), eating the food ($n = 36$ [21%], "their kids are now 'bite proof' at 8 peanuts a day or more for their maintenance dose"), fear of OIT ($n = 37$ [21%], "I know there is a risk with treatment"), and the child's preference ($n = 8$ [5%], "some kids aren't consuming the allergen consistently after the therapy") (Table 2).

Subthemes were indicative of the caregiver's motivation for pursuing OIT, including fear of the food allergy ("My hope is she won't have to live with anxiety and fear with eating"), the goal of eating the food ("The point is to become desensitized to peanuts. To be able to eat freely"), discussion about cross-contamination ("I am really hopeful that this will give him a safety net and allow him to be more social with less stress.") or reasons to avoid OIT, including fear of OIT itself ("Be aware of the increased risk of Eosinophilic gastrointestinal diseases (EGIDs) with OIT") as well as child's preference ("he doesn't like eggs but has to eat them every day") (Table 2).

Logistics Theme

The logistics theme includes subthemes such as physician availability ($n = 79$ [45%], "There are a couple of

local doctors who do the therapy”), participation in and information with regard to research studies ($n = 33$ [19%], “Yeah, it’s in the trial phase”), cost ($n = 14$ [8%], “Money is a real factor for people”), and characteristics of the child ($n = 42$ [24%], “Our allergist said that the kids need to be verbal so they can communicate any symptoms they have like a tummy ache when the therapy is given”) (Table 2). Some of the physician availability posts indicated that the user’s physician did not provide this treatment (“I asked about it and our allergist said no way”) or discussed involvement of a child in a research study (“I have a friend with a now 7 year old who has been doing this study for over a year”) versus discussion of using research outcomes in their decision-making process (“I’ve read up on the studies, and they do seem promising”) (Table 2). Posts discussed the cost of the therapy (“OIT isn’t covered by our insurance”) and required characteristics of the child (“We will be doing this once LO [little one] is a little older”) (Table 2).

Questions Theme

Users approached the forum to gain more information about OIT. The questions theme had two sub-themes: questions about people’s experiences ($n = 23$ [13%], “I’d also love to hear if anyone has experiences with OIT!”) and OIT details ($n = 9$ [5%], “How does eating a little of something make the allergy go away?”) (Table 2). Overall, caregivers asked questions in 32 posts (18% of the posts included).

DISCUSSION

This mixed-methods study aimed to understand perceptions of OIT for food allergy through blog posts and comments on a popular parenting web site. Understanding caregiver priorities that may not be relayed during the health visits may help to guide shared decision-making when discussing OIT. We identified how caregivers discussed OIT in a forum where they may feel more comfortable voicing their concerns and feelings as opposed to a visit with their clinician. Through this analysis, physicians can better understand caregiver’s fears as discussed with their peers. This knowledge may facilitate how physicians share information and counsel patients and families. When caregivers express attitudes with regard to OIT, a major attitude is fear (39%, combining fear of a reaction and fear of OIT). Caregivers are fearful of their child having an allergic reaction, which drives their decision to pursue OIT as a protection for their child (17%) (Table 2). In addition, they are fearful of the OIT itself and concerned about adverse effects and the possibility of the therapy causing a reaction (21%) (Table 2). This suggests that the decision to pursue OIT treatment is driven by caregiver concern. Therefore, there is a need for clinicians to communi-

cate in an effective and supportive manner when counseling caregivers with regard to OIT.

Providers very rarely solicit caregiver concerns or opinions, but this information can be helpful to both patients and providers in determining the best step in the management of a patient’s food allergies.³³ Provider empathy is an important component of the relationship, and understanding patient motivations and fears for treatment is key, especially when deciding about OIT, which is in equipoise for many patients. This is often the case for elective treatments or procedures, in which patients compare risks and benefits in the context of their own goals and values, and may decide that the best option is to not pursue the treatment.^{34,35} Expressing empathy is a key aspect to the patient-centered communication approach, which could encompass naming the patient’s emotion (fear), expressing understanding of that emotion, and respecting and supporting the decision.³⁶ Results of previous research showed that, for elective procedures, many caregivers approach the initial consultation with a predisposition for a certain treatment choice, which may be influenced by outside sources, such as social media and previous physician input.³⁷

Knowing how patients are discussing OIT online is important for physicians because lay persons’ perceptions will help give a more global understanding of caregiver preferences and may help physicians guide caregiver engagement. Despite the identification of these themes and subthemes, each caregiver will have his or her own opinions, fears, and motivations about food allergy treatment. Recent publications with regard to food allergy and shared decision-making emphasize the importance of establishing the patient’s values and opinions, and in not assuming that those of the physician are those of the patient.^{15–17} The findings of this article can guide clinicians in counseling their patients and in adopting shared decision-making strategies, which is especially important when discussing optional elective-type procedures and therapies.^{34,38}

The limitations of this study included that using one social media site may limit the generalizability of these findings because caregivers who post on the Baby-center web site may not be representative of all caregivers of children with food allergy.²¹ It is possible that caregivers who post on social media have more overt opinions and experiences with OIT than the general population.²¹ The sample size may not have captured all of the opinions of those posting on social media. In addition, certain users posted multiple times, and, as such, attitudes of fewer users may have distorted the themes observed. The qualitative methods used in this mixed-methods approach are subject to bias by the researcher, which we attempted to reduce through double coding. The quantitative analysis was descriptive in nature. Searching online forums for terms may be limited given the type of language and symptoms

used, and defining the search in this way may have missed relevant content.²¹ Future research could evaluate other forums geared toward the general population, including Twitter (Twitter, San Francisco, CA) or other parenting forums.^{21,22} To further understand caregiver perceptions and attitudes with regard to OIT for treatment of food allergy, clinical studies carried out in hospitals and in medical centers are necessary. Despite these limitations, to our knowledge, this was the first study in the literature to use social media to assess caregiver opinions with regard to OIT for food allergies and provided a framework for shared decision-making between physicians and caregivers with regard to OIT.

CONCLUSION

This study showed that social media is a powerful tool to be harnessed in future research that is farther reaching. This study aimed to understand caregiver perspectives of OIT as reported on a popular parenting web site. We identified perspectives on OIT that caregivers discussed with other caregivers. These findings may help guide clinicians in counseling their patients on available treatments for food allergy and help inform shared decision-making strategies for treatment with OIT.

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